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Huntington's disease in the news and entertainment media - Part II: A suicide on TV

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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About Me

MONDAY, NOVEMBER 07, 2011

Huntington's disease in the news and entertainment media – Part II: A suicide on TV

I'm not going to die a slow death from Huntington's. I'm not going the way my mother did.... It's time, Amelia. I mean, I've had great food, great sex, great love in my life, and a great friend. I'm happy, and I'm ready. I need you to help me die.

With those words, 30-year-old Michelle, whose HD symptoms had recently started, asks her doctor to assist her in committing suicide.

Michelle and Amelia are fictional characters in the ABC television network's evening drama *Private Practice*, but the scenes in which they act (broadcast on October 27, 2011) represent the stark psychological reality of HD patients, untested at-risk individuals, and gene-positive people like me.

According to a 2005 landmark study of HD and the risk of suicide conducted by the international Huntington's Study Group (HSG), HD patients commit suicide an estimated seven to 200 times more often than the general population, although the data are complex because of the diverse scientific methodologies employed in the research. "Indeed, our current ability to predict actual suicide is poor," the study states ([click here](#) to read more).

A 2010 [article by Dutch medical school professor Raymund Roos](#) reported that after pneumonia, the leading cause of death in HD patients is suicide.

Other studies have demonstrated that suicide risk increases around the time of genetic testing for HD ([click here](#) to see one example).

In the *Private Practice* episode, Michelle goes through with her plan, only to change her mind when an injection applied by Amelia leaves her unable to breathe. After her revival in a hospital emergency room, Michelle makes another attempt, this time alone. Amelia discovers her dead body on top of a bed with an open bottle of pills at her side.

Disturbing thoughts

This was an even more painful depiction of HD in the popular media than, as I described in Part I of this two-part series, the *Dear Prudence* column recounting the story of a young mom who learned just days after the birth of her son that her mother-in-law had HD. That news signified that the father and the baby were also at risk for HD, putting the dad and possibly the son in the difficult situation of requiring a genetic test. [In the article I recalled my own anxiety-ridden process of decision-making](#), which led to my positive test for HD in June 1999 and, six months later, my daughter's negative test in the womb.

Thinking about the *Private Practice* episode stirs up disturbing recollections of my suicidal thoughts in the years before and after my



[View my complete profile](#)

HD Links

[Huntington's Disease Society of America](#)

[International Huntington Association](#)

[Huntington's Disease Drug Works](#)

[Huntington's Disease Lighthouse](#)

[Hereditary Disease Foundation](#)

[Huntington's Disease](#)

[Advocacy Center](#)

[Thomas Cellini Huntington's Foundation](#)

[HDSA Orange County \(CA\) Affiliate](#)

[HD Free with PGD!](#)

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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)

[Angela F.: Surviving Huntington's?](#)

[Heather's Huntington's Disease Page](#)

genetic test, although not at the moment of the test itself.

My mother had been diagnosed with HD in 1995. Distressed, I watched her revert to a childlike state. I remember vividly how, during one of her visits at our San Diego condo, she ate with her hands. She was also rapidly losing the ability to speak.

“I don’t want to be a gimp,” I remember angrily telling myself, fearing that I might have the HD gene and would become severely disabled.

A farewell ceremony

As a Catholic, I had grown up with the belief that suicide was a sin. As an adult, I still considered it wrong as well as a terrible waste of a human life, no matter what the condition of the person. Life was a gift from God, and only God could take it away.

But HD so relentlessly destroyed my mother’s humanity that I began to think differently about suicide.

On several occasions I declared to my wife that I would rather end my life than face HD symptoms.

I especially feared losing my ability to pursue my greatest passions, reading and writing.

I created a film in my mind in which I invited my closest friends and my wife to a farewell ceremony after which I would, like Socrates, drink a cup of poison.

With a mixture of fear and bravado, I even told my wife about this plan.

Whenever we spoke about HD, she would offer words of hope. However, she kept silent on the topic of suicide. I could tell by the look in her eyes that these declarations scared her.

A devastating option

On the day I received my HD test results in 1999, my wife and I entered a state of emotional shock. As I pulled my new Corolla out of the clinic parking garage, I became distracted and scraped the right fender against a column.

But I did not think of suicide.

I was angry – but also filled with a resolve to fight back. Testing positive for HD changed my life forever. It cast upon me a pall of fear and anxiety, but it also energized me to live life to the fullest.

In the next few years, thoughts of suicide lingered for a while but eventually left my conscious self.

The birth of our HD-negative “miracle baby” in June 2000 – just a few weeks after the first anniversary of my positive test – transformed my thinking about HD and suicide.

First of all, I was so overjoyed at her arrival, and then so busy helping care for her, that I had much less time for dwelling on HD.

Secondly, my fatherly instinct kicked in. With a family to love and support, and who unconditionally lent me their love and support, I began to see the absurdity of committing suicide – at least while I was still free of symptoms.

[As I wrote a few years later](#), “Suicide would spare my family an exhausting,

financially ruinous burden. I would not suffer like the HD patients I recently saw at a nursing home, writhing uncontrollably, wearing diapers, belted in a special chair or confined to a padded room. But a suicide would devastate my daughter.”

Dredging up difficult feelings

So I buried thoughts of killing myself. I also channeled much of my anxiety into an increasing level of advocacy work for the [Huntington's Disease Society of America](#).

After my mother died in February 2006, [I became paralyzed by the fear of onset](#). For nearly nine months, I did not write in this blog.

Yet I had no fantasies of suicide during that long and dark night, although I most certainly thought about death every day.

Since then, I have gained psychological stability and worked hard to avoid symptoms. Surely luck plays a part in the fact that [I am approaching my mother's age of clear onset](#) without any classical signs of HD.

But watching and then reflecting on the *Private Practice* episode dredged up the difficult recollections I am sharing with you here.

Analyzing *Private Practice*

I tracked a debate among some members of the HD Facebook community about the pros and cons of the episode, especially regarding whether it accurately portrays the reality of HD people. A number criticized the program for focusing on suicide, while others welcomed the exposure HD received.

Private Practice is actually just the latest in a line of TV productions about HD stretching back to the 1960s. For a detailed explanation of that history, you can [click here](#) to watch a video of the keynote speaker at the 2009 HD research conference sponsored by the [CHDI Foundation, Inc.](#), the so-called “cure HD initiative,” backed by wealthy, anonymous donors.

The *Private Practice* episode uses HD as a vehicle to demonstrate the dilemma experienced by physician Amelia in her decision to assist Michelle with suicide.

To the extent that it portrays HD and suicide, I believe the episode is fairly accurate. I very much identified with Michelle's fears of turning out like her mother. Like her, I frequently thought of planning a suicide for a moment in my life when I could still properly say good-bye.

Suicide as preoccupation

Clearly, as the HSG and Roos articles point out, thoughts of suicide preoccupy many HD people in the at-risk, gene-positive, and affected categories.

Based on a study of “suicidal ideation” in 4,171 individuals in the HSG database, the HSG study determined several critical periods for suicide in HD: the time leading up to diagnosis, onset and the start of early “soft” symptoms (when people can still actually plan a suicide), and the period in which patients lose the ability to perform such tasks as driving and become dependent on others for daily living.

In contrast with popular belief, the HSG report emphasizes that getting diagnosed actually *reduces* suicidal thoughts: “Receiving a diagnosis of a devastating fatal disease does not exacerbate, and may even alleviate, the risk of suicide.”

Dramatizing HD

We need to keep in mind that *Private Practice* is entertainment – not a documentary.

Clearly the creators of the program compressed Michelle's experience into an extremely short period of time in order to dramatize the symptoms of HD.

All humans have a huntingtin gene with a series of components known as CAG repeats. Healthy people have ten to 29 repeats. Forty or more repeats signify that a person will develop HD. In general, the higher the repeats, the younger the onset.

My mother had 40 repeats, and so do I. Evidence demonstrates that this level of defect will lead a person to develop the disease roughly between his or her late forties and mid-fifties.

Michelle has 43 repeats and already has strong symptoms at age 30 – possible but unlikely.

She occasionally displays dance-like movements in her arms, a sign of the classic symptom of HD known as chorea. Amelia describes her as having “tremors, rigidity, seizures.”

Symptoms, but no hope

In debating assisted suicide with fellow physicians, Amelia points out that Michelle's prognosis is not good. “What if you were seizing and drooling and losing control of your muscles, of your bowels, of your mind?” she says. “Would you want to stick around for that?”

Another doctor counters that Michelle is still “lucid” and “functional” and can get assistance from a support group and other HD services.

These symptoms appear to be accurate, at least in the long haul of an HD person's existence.

However, as I observed about the *Dear Prudence* column, the *Private Practice* episode also fails to note the immense gains in research that would certainly give someone like Michelle reason to hope for a treatment or even a cure in her lifetime.

Ending a life

On the day of the incident, Michelle lies on a couch as Amelia prepares to administer the medications that will halt her life. Amelia explains that after Michelle dies, she will call the police. She warns Michelle she might end up in an irreversible coma.

“I don't want to get you in trouble,” Michelle says with worry in her voice.

“I don't want you to suffer,” Amelia responds sorrowfully but with determination to help her friend.

After the aborted first attempt with Amelia's help, Michelle expresses doubt about her decision to die. She displays an apparently renewed desire to live, and even a bit of humor in a conversation with Amelia.

However, apparently still despondent about her situation, she ends her life.

Testing and planning for the future

The program and especially the research articles about HD can serve as an

important starting point for the HD community to discuss openly one of the most difficult of issues: suicide. As the program illustrates, for an HD person and his or her physician, assisted suicide involves questions of health but also of moral values.

As I pointed out in the article on *Dear Prudence*, gene-positive individuals can contribute immensely to the quest for treatments and a cure.

After testing, I became “Gene Veritas,” the truth in my genes. If you are an at-risk individual, you can discover your own truth – and plan for it accordingly.

I believe that *in my personal case*, I would have had more suicidal thoughts had I not been tested.

Obviously, a decision to test is a highly personal one. But, with the increased understanding of HD resulting from research, it’s time for our community to see it in a new light.

Feeling mortal

At the same time, I admit that I deeply fear the moment of onset. I realize – from reading the HSG study but also in consulting my heart – that the fear of becoming a “gimp” could potentially lead me to act like Michelle.

We all deny death on a daily basis. Without that denial, we couldn’t function as individuals and as a civilization.

After my mother’s diagnosis, I was forced to confront the idea of a horrible, early death. I have learned to become especially skillful in my use of denial.

But how will I perceive my life when the inevitable onset begins? I dread that moment.

Watching *Private Practice* and writing about it have once again left me feeling painfully insecure – and mortal.

Posted by [Gene Veritas](#) at 6:27 PM



Labels: [assisted suicide](#) , [at-risk](#) , [CHDI](#) , [cure](#) , [denial](#) , [diagnosis](#) , [disabled](#) , [gene-positive](#) , [genetic test](#) , [genetic testing](#) , [HD-negative](#) , [Huntington's](#) , [nursing home](#) , [onset](#) , [suicide](#) , [symptoms](#) , [testing positive](#) , [treatment](#)

2 comments:

Anonymous said...

Thanks for the insightful writing.

Megan

[8:54 PM, November 07, 2011](#)

Anonymous said...

Wow. I tested positive, and I feel very much like the character in the episode. I was symptomatic at age 30. I was just thinking about suicide as it relates to HD today. I guess it's different when you're married, and certainly if you have children. I have neither. Thank you for this..it brought me to tears.

[10:12 PM, November 07, 2011](#)

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